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African American Living Donors' Attitudes About *APOL1* Genetic Testing: A Mixed Methods Study

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Abstract

Rationale & Objective: African American (AA) live kidney donors ('donors') have a greater risk of kidney failure than do European American donors. Apolipoprotein L1 gene (*APOL1*) variants in AAs may be associated with this disparity.

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Study Design: Cross-sectional, mixed-methods design.

Setting & Participants: AA donors at one transplant center.

Analytic Approach: Semi-structured interviews assessed attitudes about *APOL1* genetic testing, willingness to undergo *APOL1* testing, hypothetical decisions about donating with two *APOL1* variants, and demographics. Surveys assessed perceptions of ethnic identity and genetics knowledge. Interview transcriptions were analyzed using thematic analysis. Survey data were analyzed using descriptive statistics.

Results: Twenty-three donors participated in semi-structured interviews. Most (96%) reported that transplant centers should routinely offer *APOL1* genetic testing to all AA potential donors. Most (87%) would have been willing to undergo *APOL1* testing before donating. Although study participants noted that *APOL1* testing may deter AA potential donors from donating, most (61%) would have donated even if they had two high risk *APOL1* variants. Several themes emerged. Study participants believed that *APOL1* testing would have provided information helpful to donors' ability to make informed donation decisions. Participants expressed concern about *APOL1* variants placing donors at harm for kidney failure and, therefore, valued taking preventive health measures. Participants believed that potential donors would experience psychological distress from learning they have two gene variants and could harm their recipients. Participants were apprehensive about insurance coverage and costs of *APOL1* testing and feared that *APOL1* genetic test results could discriminate against AAs.

Limitations: Findings may not be generalizable to AA potential donors.

Conclusions: Findings suggest that AA donors support *APOL1* genetic testing, yet fear that *APOL1* variants and genetic testing could adversely affect donors' health and ethnic identity. Transplant centers using *APOL1* genetic testing should address AA donors' concerns about *APOL1* genetic testing to optimize future donors' informed consent practices.

Keywords

African American; ethics; ethnicity; health disparities; informed consent; kidney transplantation; living donation; sociocultural; medical decision making; genetic testing; apolipoprotein L1 (APOL1); cultural identity; qualitative research

Introduction

Living donor kidney transplantation (LDKT) has become standard of care given its advantages over deceased donor transplantation.^{1,2} However, live kidney donors (henceforth 'donors') have a greater risk of kidney failure than healthy non-donors post-donation.³⁻⁵ African American (AA) donors have a greater risk of kidney failure post-donation than European American donors.^{3,4} Risk variants in the Apolipoprotein L1 gene (*APOL1*) may contribute to this disparity because they are significantly associated with kidney failure predominantly in AAs.^{6,7} Evidence from deceased donor kidney transplants suggests that donors with *APOL1* variants may place recipients at greater risk of transplant failure.⁸ Recent research found that AA donors with two *APOL1* risk variants had a significantly greater decline in post-donation kidney function than those with one or no gene variant.⁹

These findings have generated concerns in the transplant community over protecting donors' health and improving informed consent.^{10,11} As a precaution, some transplant centers provide AA potential donors with *APOL1* genetic testing,¹² despite the American Society of Transplantation's recommendations against routine testing.¹³ Little is known about AA donors' attitudes about *APOL1* testing, and how they would respond to being offered *APOL1* testing currently, or in the future should the NIH-issued *APOL1* Long-term Kidney Transplantation Outcomes Network (APOLLO) trial find evidence to support testing.

AAs' attitudes about genetic testing vary. Most AA first-degree family members of end-stage renal disease (ESRD) patients surveyed were willing to receive genetic test results regardless of available treatment options (90%), and would share results with family if informed of having a disease risk variant (92%).¹⁴ AAs' attitudes about genetic testing are shaped by cultural beliefs (e.g., a present time orientation),^{15–18} and ethnic/racial group identity.^{16,18}

As attitudes predict behaviors,¹⁹ understanding AA donors' attitudes about *APOL1* testing and cultural identity may reflect future donors' receptivity to genetic testing, willingness to donate, and may affect the donor informed consent and evaluation processes. Our study aimed to assess AA donors' attitudes, hypothetical decision-making, and information needs about *APOL1* testing.

Methods

Approach

Mixed-methods involving semi-structured interviews with surveys were conducted sequentially, driven by an ethnographic methodological approach. Semi-structured interviews assessed AA donors' attitudes about *APOL1* testing, and surveys assessed donors' racial/ethnic identity and knowledge about genetics to contextualize their attitudes. Mixed-methods enabled elaboration and clarification, increased validity of results, and informed subsequent data collection.²⁰ Validity or "credibility"²¹ of interpretations was attained by employing multiple methods, theoretical approaches, and multidisciplinary team member checking.²²

Sample Population and Recruitment

Donors eligible for participation were: age ≥ 21 years, AA (identified in the medical record), English-speaking, and had donated within the past 20 years. Donors were recruited consecutively by mailed letter or email, signed by the Principal Investigator (EG) and a transplant nephrologist (JF) to introduce the study. The letter included a fact sheet describing *APOL1* variants and genetic testing. Two female research staff (one African American, one Hispanic) with master's degrees and training in qualitative interviews (DA) contacted donors by telephone a week later to review the study and schedule an interview. Northwestern University's Institutional Review Board approved the study, and verbal consent was obtained.

Data Collection Methods

Semi-structured interviews were conducted by telephone, and included 49 open-and closed-ended questions about donors' attitudes and hypothetical willingness to undergo *APOL1* genetic testing; decision-making about donation in hypothetical scenarios; information needs about *APOL1* testing; perceptions about the impact of genetic testing on the AA community; and demographics (age, gender, education, marital status, income level, primary insurance, self-identified ethnic identity,²³ time since donation) (Table S1). Cognitive "think aloud" interviews were conducted by telephone with a convenience sample of 5 AA donors to assess their understanding of interview questions and refine questions for clarity.²⁴ Cognitive interviews lasted 50–75 minutes and hand-written notes were taken. Participants were compensated \$15 for their time. Semi-structured interviews were then conducted using standardized approaches until reaching theoretical saturation.^{25,26} Interviews lasted 25–60 minutes and were audio-recorded. Participants then completed telephone or online validated surveys about their knowledge of genetics and racial/ethnic identity (Table S2). Participants were compensated \$20.

Qualitative Analysis

Interview transcripts were analyzed for themes and patterns emergent from the data²⁷ using the constant comparison,²⁸ and inductive and deductive coding methods.²⁹ All audio-recorded interviews were transcribed. The research team (EJG, DA, IB) developed an initial deductive code list *a priori*, based on interview domains (e.g., decision making, willingness to donate, information needs), and iteratively openly coded the first set of 3–5 transcripts and notations. The research team independently applied codes to new transcripts, revised the coding scheme for new responses, and applied modified codes to prior transcripts. This process was repeated until reaching thematic saturation.³⁰ After coding each set, the team compared codes and resolved discrepancies to reach consensus in code definitions to establish the preliminary codebook.³¹ A set of 5–6 analytic retreats entailed reviewing the codebook, clarifying interpretations, and revising codes. After finalizing the codebook, new transcripts were independently coded by two research staff (DA, IB) until establishing inter-rater reliability ($Kappa > 0.80$).³² Thereafter, all transcripts were coded. Coded segments were reviewed for themes and patterns, with further discussion to reach consensus. Qualitative analysis software (MaxQDA)³³ was used to support analysis. Representative quotations are provided to illustrate key themes.

Statistical Analysis

Descriptive statistics (e.g., frequencies) assessed the distribution of responses across the sample using the Statistical Package for the Social Sciences (SPSS) v.23 (Chicago, IL).

Results

Demographics

Of all eligible participants contacted ($n=45$), 62% participated in an interview, while 38% refused (Figure 1). Participants were mostly women (87%), and had a mean age of 47 years (Table 1). All donors had adequate health literacy levels, and most were college graduates

(61%). Participants donated a mean of 8 years ago to their sibling (44%), parent (22%), or child (17%), and all were in excellent, very good, or good health.

Cultural Identity

Donors had moderate levels of Black racial identity and Africentrism (Table 2). Participants had a low present-time orientation and a moderate future-time orientation, which may better enable AA donors to consider the potential value of *APOL1* genetic testing as it requires consideration of potential future events.

Knowledge and Attitudes about Genetic Testing

Participants had moderate knowledge of genetics (mean, 6.7 $\pm$ 1.4 [SD]), moderate to high levels of genetics literacy (means of 6.3 $\pm$ 0.8 and 6.9 $\pm$ 1.3 for familiarity and fill-in-the-blank, respectively), and a high level of genetics self-efficacy (mean, 10.4 $\pm$ 6.0) (Table 2). Attitudes were generally supportive of *APOL1* testing (Table 3).

Initial Impressions of *APOL1* Genetic Testing

Donors' initial impressions were generally positive, and can be thematically grouped into benefits of *APOL1* testing, concerns about risks, fears about discrimination or stigma, and concerns about insurance (Box 1).

Benefits of *APOL1* Genetic Testing—The main benefit of undergoing *APOL1* testing was gaining knowledge about the potential donor's own risks of kidney failure to make more informed decisions about donating. *APOL1* testing “would just give them [potential donors] an alert, ‘Hey! This is what possibly could happen. I’m letting you know, if you do possibly give your kidney away, it is possible that it might affect you in the future. You might actually wind up having kidney failure as well.’ ... So it gives them... a *choice* to say: You want to do it [donate], or you don’t?” (5023)

Some said test results could help doctors to better monitor donors' health, and prompt donors to take health precautions (e.g., dietary changes) to prevent kidney failure. Test results could help donors “create an action plan in regards to [their] health” by “being proactive versus reactive.” (5015) Lastly, genetic test results could help recipients learn about their own risks of accepting the donor's kidney to inform their own decisions.

Concerns about *APOL1*—Donors expressed concerns about the risks of having two *APOL1* variants (Box 1, Box 2). The most salient subtheme was that having two gene variants might place donors at harm by causing kidney failure and reducing life expectancy post-donation. One donor questioned: “What are my risks of being a donor?... What are my risks as far as how long will I live, even if I give one kidney? If I give a kidney and I still have one, am I susceptible to any other diseases than having just one kidney? Will that affect me even more, just having one kidney?” (5003) Others wondered how donors could respond to having two gene variants: “...Just what things could I do to prevent my potential for developing kidney failure? Are there changes I can make to my diet?” (5011)

Most donors would have donated despite having two gene variants. Yet many anticipated that the increased risk of kidney failure may deter future donors who have two variants from donating. One remarked: “If someone were willing to be a donor and they found this variant, it could preclude them from actually going through with the donation process. But since, I guess, research hasn’t definitively concluded that it would necessarily be harmful in people who get kidneys from a living donor, I don’t know if that *should* affect their decision.” (5005)

Another subtheme was that donors would experience a “traumatic” or “devastating” psychological toll from having two *APOL1* variants. Donors explained that uncertainty about whether having two gene variants adversely affects donors’ health could be “nerve-wracking.” Donors also expressed concerns about harming the recipient by donating a kidney with two *APOL1* variants.

Discrimination and Stigma—Most donors did not think that *APOL1* testing results would present a risk of discrimination against AAs. Yet some believed the AA community may be suspicious because *APOL1* testing would only be “marketed” which may potentially stereotype or “target” the AA community. Thus, donors stressed the importance of gaining the community’s “trust.” Some donors talked about possible discrimination against potential donors by transplant programs not clearing them to donate, or by potential recipients declining the donor’s kidney. One remarked, “I definitely think that stigma would be *there*... hospitals or doctors when trying to find a potential kidney donor for someone, obviously, if they came across that information,...that would definitely play into... whether or not they accept a living donor who has that gene...” (5005)

Insurance—Another theme was participants’ uncertainty over whether health insurance carriers would cover the cost of *APOL1* testing, and if insurance rates would increase among donors with two *APOL1* variants. Some feared that having *APOL1* variants would comprise a pre-existing condition, and may lead insurance carriers to discriminate against AAs. One stated, “I believe there will be another stigma targeting the African American community. It could have... economic repercussions because African Americans, we always feel like we have to pay more for a lot of things anyway. So, we would probably have to pay even more for medical insurance, life insurance,... each time something is tied to us exclusively, like in higher numbers. Then that makes our things more expensive, for instance, health insurance.” (5009)

Willingness to Get APOL1 Genetic Testing

Most donors (87%) were “entirely” or “a lot” willing to have gotten *APOL1* tested before donating, while few were somewhat (9%) or not at all (4%) willing. Donors were motivated to get tested to: learn about their own risks, prepare for potential harms to their remaining kidney, and help the recipient (Box 1). “Again, just to make sure that say, my kidney is as viable for my sister as possible. And then to screen me for any potential risk down the line.” (5004) Donors were not motivated to get tested because they would have donated regardless of the test results, or feared that test results might have swayed their decision against donating.

Hypothetical Decision Making

Most donors would have donated if they had tested positive for two gene variants (61%), while a third was unsure (35%), and one would not (4%). Reasons for donating included saving the life of their loved one, and insufficient data and uncertainty about getting kidney disease from two *APOL1* variants (Box 1). “My son has some health issues, and I was willing to do whatever I could to help him to either extend his life or have a better quality of life.” (5012)

Some donors also believed the benefits to the recipient would outweigh the risks to donors given limited current knowledge on potential harms to donors. “That was my sister. I loved her. And the fact that the surgery only lasted a short period of time, the pain of losing my sister would last a lot longer. That would be something I would have to live with. That’s just the pain... That was my logic: the pain of losing my sister would last me a lifetime, versus the surgery you’re having.” (5003)

Donors unsure of or opposed to donating with two *APOL1* variants said they would have wanted to confer with their recipient or physician. “I would consider it, I guess maybe,... [Knowing that if I donate then I would be at risk, versus if I donated and I *knew* I wasn’t going to be at risk. That would kind of sway my decision. I kind of just jumped on board when I found out my mom needed a kidney. I really didn’t hesitate. But if there’s another factor in it, like this genetic mutation, then I would kind of consider it.” (5000)

All donors said that they would have donated with one gene variant because the risk to themselves was lower.

Expectations about Offering APOL1 Genetic Testing and Decision Making about Donating

Most donors (96%) agreed that transplant centers should routinely offer *APOL1* testing to all AA potential donors. Most donors believed that transplant centers should allow donors with two gene variants to donate (65%), though some were unsure (17%), or were opposed (17%). Donors in favor reported that it is ultimately the donor’s decision to donate, as long as donors are well informed about the risks, while those opposed or uncertain said that donating posed too much risk to donors.

APOL1 Genetic Testing Post-Donation

Most donors said they would get *APOL1* testing now, after having donated (78%), while others would not (13%), or were unsure (4%). Donors related that test results would be valuable for being informed and stored in medical records. “I would see what I can do to prevent getting kidney disease, if I did the test and found out I actually had the gene. I’d try to do whatever I need to do to prevent any type of health issue.” (5025) Others wanted to inform family members that they might have a risk of kidney disease to take preventive action, if possible. Those against testing believed that it would be too late to use this information post-donation.

Informing Potential Recipients about APOL1 Test Results

Most donors (78%) believed that potential recipients should be told about their donor's *APOL1* test results because the results could affect them (Box 1). However, some were opposed (17%) or unsure (4%), considering that results should be kept confidential, and the decision about disclosure should be the donor's.

Communicating APOL1 Test Results

All donors reported that *APOL1* testing should occur early in the donor evaluation process (e.g., during initial blood work) (Box 1). Performing the test early would help prevent recipients from getting unnecessarily excited about donor eligibility, and save donors from undergoing further testing.

Impact of APOL1 Testing on the African American Community and Identity

Most donors believed that *APOL1* testing would positively impact the AA community (Box 1). Some said the community would be open to testing as a way to educate people about donation and help potential donors know whether they are healthy enough to donate. Others believed that *APOL1* testing would benefit AAs by providing information about medical issues that affect the AA community more broadly. One stated, "I think as a community it will help us to be better educated about our health and our genetic predisposition for kidney failure, and hopefully what things we can do within our control to try to combat some of those factors." (5011)

By contrast, some donors believed that *APOL1* testing would not be well received by some in the community because AAs would be unfamiliar with *APOL1* testing, or would question its financial impact on them. Few noted that the AA community may be less open to testing given the history of distrust of the healthcare system. "This is two-sided. There are some people in the African American community that will say, 'Yes. Get it done. It is for our good.' Especially those that are educated. But there was all the conspiracy of everything that's happened in America. People will go back to the Tuskegee study and so many other studies, and then it may be frowned upon." (5007) Some AA donors bemoaned how *APOL1* constitutes yet another health condition specific to AAs that is added to "our list" of conditions to manage (e.g., hypertension, diabetes, sickle cell anemia), which may further stigmatize AAs. Donors wanted to better understand how *APOL1* variants are related to AA identity, namely, how and why *APOL1* variants came to affect primarily people with an African heritage (Box 2).

Discussion

Our findings suggest that AA donors support *APOL1* genetic testing early in the donor evaluation process. AA donors highly valued the potential of *APOL1* genetic test results for enhancing their informed decision making process. Although some donors feared that two *APOL1* variants would dissuade AA potential donors from donating, most donors would have undergone *APOL1* testing to understand their health risks and take health precautions to prevent kidney failure post-donation. Other research similarly shows that genetic testing prompts patients to adopt protective lifestyle changes.^{34,35} Such precautions are important

considering that hyperfiltration of the remaining kidney may be a ‘second hit’ triggering kidney disease.

In other clinical contexts, AAs have more negative attitudes about genetic testing than European Americans^{16,36–38} due to AAs’ lack of knowledge about genetics,^{39,40} distrust in the healthcare system,^{41–44} beliefs,⁴⁰ and systemic barriers.^{45,46} Despite expressing some distrust of the healthcare system, donors may be more receptive to genetic testing because of their ‘altruistic’ disposition to help family, and high level of genetics knowledge. Additionally, test results may help donors weigh the risks and potential benefits of donation on their recipients and themselves. Still, some donors voiced concern about *APOL1* variants as yet another condition that disproportionately afflicts AAs. Other research found that AAs were significantly less willing to donate genetic material for research than Whites⁴⁷ because of potential racial/ethnic discrimination. Such research corroborates our findings that AAs’ decisions about genetic testing involve considering the implications of donating to themselves, and to the broader racial/ethnic group with which they identify.

Participants expressed concerns about insurance carriers discriminating against AAs with two *APOL1* variants by increasing insurance premiums or denying coverage. If insurance does not cover *APOL1* testing, or if out-of-pocket costs are too high, donors may become reluctant to pursue *APOL1* testing. Consequently, disparities in AA donor and recipient outcomes might become unintentionally reinforced.

The transplant community recommends informing all AA potential donors about the association between *APOL1* risk variants and increased risk of kidney failure, the limited ability of *APOL1* testing to predict kidney failure, and the opportunity to undergo *APOL1* testing.^{13,48} However, most donors in this study believed that transplant centers should *routinely* provide *APOL1* testing to AA potential donors. Transplant programs offering *APOL1* testing should address potential donors’ information needs about *APOL1*, and the risks to donors and recipients when donating with two *APOL1* variants. Programs should also be prepared to counsel donors experiencing psychological distress from having two gene variants, a common response among patients undergoing other genetic tests.^{49,50}

A key finding was that most AA donors would hypothetically choose to donate regardless of having two *APOL1* variants, despite uncertainty over potentially developing kidney disease post-donation. Thus, offering *APOL1* testing would enhance AA donors’ informed consent process, while minimally increasing the likelihood that donors would decline donation. A survey found that half (50%) of 383 transplant physicians would not proceed or strongly recommend against donation with two gene variants.⁵¹ Given donors’ and providers’ different preferences, discussions are needed to further elucidate this discrepancy and provide guidance about whether donors with two gene variants may donate and standardize clinical care. Transplant clinicians and community nephrologists should be prepared to manage more AA donors with two gene variants given their potentially higher risk profile.

Toward these ends, we are designing culturally targeted transplant educational materials for counseling AA potential donors about *APOL1* testing, which may facilitate greater comprehension,⁵² enhance donors’ informed decision-making process, and promote patient-

centered care. Future research should evaluate the effectiveness of these educational materials on transplant providers' and AA potential donors' decision-making for *APOL1* testing,⁵³ and assess AA potential donors' decisions about *APOL1* testing and donation.

This study has strengths and limitations. A strength is that this study qualitatively assessed AA donors' perspectives on *APOL1* genetic testing, as has been called for.⁵⁴ Although recruiting AAs and donors into research can be challenging, our study engaged AA donors to give voice to important issues affecting the AA community. As a single center study, our findings may not be generalizable to donors in other geographic locations.

Our study included former donors because at the time of data collection, *APOL1* testing was not routinely performed per clinical practice guidelines.¹³ Thus, the sample of AA potential living donors being offered *APOL1* testing was not available for recruitment. Additionally, *APOL1* testing is controversial,^{11,12,34} and the field remains in equipoise. Therefore, we believed that including former donors was the most ethically sound approach for this study. Including potential living donors might have influenced our findings. Former donors' prior donation experiences may have reinforced their receptivity to living donation even with two *APOL1* variants. However, the possibility of having two *APOL1* variants could have compounded potential donors' ambivalence about donating.

As most participants were female, nearly age 50, and had good health, as found elsewhere,⁵⁵ a selection bias may have influenced findings. Donors' health status and age could have influenced their hypothetical decisions about donating with *APOL1* variants. However, the large time span since participants donated afforded the opportunity to see if donors had experienced declining kidney function, which may have informed participants' perceptions. Findings may not be transferable to males. Although our sample size was typical of qualitative studies,⁵⁶ it may limit the study's generalizability. Future research should assess gender, health, and age differences in donors' perceptions of *APOL1*. Participants' responses in favor of donating with two *APOL1* variants may have been influenced by social desirability bias, and by being dedicated to helping their close family members. Responses may have been influenced by how information was presented in the fact sheet. Although the fact sheet statement, "*APOL1* gene variants might lead to African American living donors' greater risk of kidney failure," was implicitly based on a comparison to African American living donors who don't carry these two variants, this comparison was not made explicit in the fact sheet and thus, to study participants. Further, the fact sheet did not state that it is unknown whether kidney donation confers an increased risk of kidney failure compared to non-donation among expressers of two gene variants. Hypothetical decisions may not reflect donors' actual decisions. AA donors' attitudes may change in the future, depending on prior exposure to genetic testing, and how common *APOL1* testing becomes.

In sum, our findings suggest that some AA donors are receptive to undergoing *APOL1* testing. Many would donate with two *APOL1* variants despite uncertainty over the potential for developing kidney disease post-donation. Donors desired greater information on how two *APOL1* variants affect donors' health, and insurance coverage for genetic testing. Donors cautioned about potential discrimination. Future research should assess AA potential donors' willingness to donate with two *APOL1* variants, and potential recipients' attitudes about

accepting a kidney from a donor with two *APOL1* variants. Our findings have generated social and ethical insights into the emerging use of genetic testing for donors, consistent with the NIH's precision medicine initiative,⁵⁷ and can inform transplant and nephrology clinical practice.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

AA	African Americans/Blacks
AST	American Society of Transplantation
<i>APOL1</i>	<i>Apolipoprotein L1</i>
APOLLO	<i>APOL1</i> Long-term Kidney Transplantation Outcomes Network
ESRD	End-stage renal disease
LDKT	Living donor kidney transplantation
NIH	National Institutes of Health

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Illustrative Quotations by Theme and Subtheme

Theme: Benefits of *APOLI* Genetic Testing

Subtheme: Help donors make informed decisions

“It helps you make an educated decision about being a living donor and how life may be affected post op. I think it’s also helpful for your physician on-going to know the results of your *APOLI* testing, so that they can advise you on any changes that are needed to your diet or any medications that could be impacted by the *APOLI* results, or to kind of provide you with guidance on nutrition and how to better take care of yourself based on the results of that testing.”

(5011)

“First of all, it’s important that people know what they know. Full disclosure. That’s the first thing, because once you know, once you have an idea of what the possibilities are, it can govern your diet, how you deal with things psychologically. It can govern your decisions. So it has a great impact all the way around. You know, of course, we’re really pushed to make more decisions as it pertains to being donors. That’s great. But it’s also great to know that they--, what are risk factors that are involved as well.”

(5006)

“Well, knowledge. Knowledge. Always. Okay, I mean, if I’m a two [gene variants], and they determine this, then, my main question is, ‘Okay, what do I need to do to avoid having going into kidney failure?’”

(5002)

Subtheme: Help monitor the donor’s health

“I definitely think that [*APOLI* gene variants] would be a big factor in their [donor’s] decision on whether or not they actually go through with the process [donating]. If they kind of knew up front what the risk would be for the person getting the donation, and how their body would respond to it. [Interviewer: Did you see any other type of benefits to potential living donors for getting tested?] I could see the usefulness in knowing that information, just so your own physician can monitor your health and your overall wellness.”

(5005)

Subtheme: Help the recipient make informed decisions

“The benefits is [*sic*] that they [potential donors] can make an informed decision about donation. So to help them and the recipient, they’ll be aware of their risk, what they’re doing, considering donating. ... Also, the recipient would be aware, ‘Oh, if this person carries this gene, then do I want to go through with the donation from that person?’”

(5025)

Theme: Concerns about *APOLI* Genetic Testing

Subtheme: Risk of the donor's kidney failure

“Well, I guess if back then when I was in the mindset of donating, I was pretty much just, is this going to put me at risk for renal failure myself. So, had I known this, had I known more about this ... I may have thought twice about doing it. Probably not, but, I may have just paused for about a split second instead of being so gung ho about it. It's just for a split second. It's just the idea of saying, 'Hey! Well, your sister is going through renal failure now, and you could be on the same boat.' So like, ahh! But then I would say, 'Yeah, but that's life. I've still got to go ahead and do it for her.' So it's not a big deal.”

(5004)

Subtheme: Risks to donor's psychological health

“I might have kidney failure [laughs]. The fact that you might ... spend the rest of your life trying to figure out if you're going to be okay. The fact that you don't know what it [the risk] would be. It is the lack of knowledge... it's really scary. I mean, that's a *huge* risk. It's psychological risk, it's a physical risk, it's a mental risk. It's risk across the board. You're like throwing darts in the dark because you don't know. You don't have access to all of the information. And certainly you can't manage something that you don't have knowledge of, but you don't have access to. It may exist, it may not exist. But if you *know*, you know how to deal [with] something [like] that. What you don't know, you don't know how to deal with it or manage it.”

(5006)

“Mentally. It takes some mental strain, I'm sure of that. I'm sure of that. Psychologically not everyone is stable enough to take on some news like that. ... I see it as psychological counseling that will be needed. It's not an easy pill to swallow.”

(5015)

“It would be a little nerve-wracking, actually, to be on the fence and not know the exacts, and things like that. I just think that, I mean, it would be a little nerve-wracking for the donor to not know [the odds of kidney disease if one has a two gene variants].”

(5023)

“[I]t's just probably just a little bit more to worry about in life. That's all.”

(5019)

Subtheme: Donors' need to take health precautions

“Just my health after donating like how [would] my future look like? What would I have to do? What precautions I would have to worry about, or how would I have to stay healthy to try to avoid kidney failure?”

(5016)

Subtheme: Risks to the recipient's kidney

“I’m not sure, that’s kind of iffy-iffy. Again, I guess if you have two of them [*APOL1* gene variants], then you are at higher risk, and then, again, you are passing it on to somebody else, so... I guess it depends on how bad it is. I mean, I don’t know how bad the condition is of having a mutated genetics like that, I guess if the person has one of the variants, they would be a better recipient. I mean, having two [gene variants] and then that it’s been passed on to somebody else is kind of defeating the purpose of the whole transplant thing then. You know? Because the recipient is getting a kidney that’s failing. But if you are having a person who has a history of it, then the potential risk, you just heighten up their risk. It’s almost like a waste of time. So those that have both can. They’re almost going to get ruled out, versus the one that has one variant can be more of a potential donor and less of a risk to the recipient.”

(5000)

“[H]aving somebody make a more educated and calculated decision, by giving them as much information as possible. Then the recipient can also look and say, ‘Hey! Well, do I really want to get cut open multiple times just in case say this kidney fails’ when they can look for a more viable kidney?”

(5004)

Subtheme: Deterring potential donors from donating

“No. I mean, if you find that there are more people with two genes, you’re going to probably find that you’re going to have less people willing to jeopardize their health [by donating]. At least African American people, especially considering some of the other factors that we already deal with, such as the high blood pressure and other medical [issues]. Fortunately, I don’t have any of those things. But now if you’re adding that risk [from two gene variants] on top of some of the other illnesses that people possess, then yeah, you’re risking their lives, and that would probably change if they were more educated or had better information.”

(5006)

Theme: Discrimination

Subtheme: Marketing to the African American community

“Because it’s African American culture, the population is the one who is mostly affected and most of the tests that will be done, it will be done mainly on African Americans, is that what you are saying? Okay. Well, I would say that historically, if there is going to be any type of apprehension within African Americans’ communities it would be because historically, when there’s some type of testing done to try and find cures for certain disease[s], such as syphilis, we were used as guinea pigs. Where we were actually injected with the viruses just to see how... and not necessarily given treatment just trying to see how it would affect the body if it was not treated like in various stages. So, the

Tuskegee study. So, with that being said and done, I think your marketing strategies or campaigning strategies have to be geared towards gaining the *trust* of the community, the population as a whole.”

(5009)

Subtheme: Not selecting or accepting donors' kidneys

“They’ll [African American potential donors] be less likely to be tested, as well as the recipients may be less likely to receive kidney donations, or trials, or tests of family members. That’ll put a heavy strain on the donation pool of people...”

(5015)

Subtheme: Not informing potential donors about the availability of APOL1 testing

“I think that there’s information that may be withheld. I mean, when you say there’s a risk, I think that they *should* be tested, if that’s what they choose once they’ve been given the information. But, certainly, it’s almost, I don’t even want to use the term that I’m thinking, when you *don’t* provide full disclosure and information. It’s almost, well, I’m going to use it, I mean... [Interviewer: Go ahead.] It’s almost criminal if you don’t share information that you know to be a possibility. ... They can be given the option to take the testing if they choose to, then it’s up them.”

(5006)

Theme: Insurance

Subtheme: Coverage of APOL1 genetic testing

“The only thing I would inquire about insurance; would the insurance cover the genetic testing? And how much would be out of my pocket, or do they offer some type of...? You know, how sometimes the hospital also has discounts or days that would open for free, or something like that. If I have to pay out of my pocket, that’s the only thing that I would be concerned [about], because that could become expensive.”

(5024)

Subtheme: Insurance discrimination against African Americans

“Yeah [chuckles] maybe the health care field would be impacted by increasing premiums [titters] on African Americans. And specifically if you get that testing done, your insurance premiums may increase. So that societal view, as well as, I don’t know like, I hate to say it but what are the outcomes of your offspring? Like are they highly likely that they’ll have it [two *APOL1* gene variants]. So, because of predisposition, negative stigma [will be] associated with anyone who had it. You know what I mean?”

(5015)

“Of course! [Chuckles] ... That probably would impact how Blacks, African Americans, are viewed from the perspective of *APOL1* testing. I’m sure that it

would impact our insurance rate. Well, let me not say that it would impact the insurance rate. I'm sure that we would be scrutinized a lot more closely as it pertains to how the insurance giants kind of work with us. So, I think that it can have some kind of trickle-down effect over a period of time."

(5006)

Theme: Willingness to get *APOLI* testing before donating

Subtheme: Willing

"If they told me it would put ... the recipient at risk, that would probably motivate me to be tested."

(5019)

"Like I said, just to get the information. You know, to have all the information available so if there were things that I needed to do, I could start getting myself ready to do them."

(5012)

"Having the knowledge of the *APOLI*. The knowledge of what it's all about and the information pertaining to *APOLI*."

(5006)

Subtheme: Not willing

"I'm going to be ... honest, and this is probably crazy, but I don't know if I would have done it. ...[B]ecause I think either way, my answer would have still been yes. You know? ... I think if I would have done it ahead of time, and found out my answer would have been 'yes.' But I would have had doubts. And I wouldn't have wanted to have those doubts in my head, like, uh...maybe I shouldn't do this. I probably wouldn't have got it done!"

(5023)

"No, I don't know about that [getting tested] because, like I said, my mind was made up about doing the transplant."

(5012)

Theme: Hypothetical Scenarios

Subtheme: Pro: donating with two *APOL1* gene variants

"You would be surprised [about] the stress of your own family member, like what I went through. That was a stressful situation. I don't want my sister to die. It was on those terms. So, I wouldn't care if I had two genes. So to save my sister, yes, I'm going to do it, take the chance. Give me the options."

(5024)

Subtheme: The benefits to the recipient outweighed current knowledge on risks to the donor

“I would have to have more information as far as, you know, more research that has to be done. I would have still donated. ... But if they told me, okay, you’re definitely going to get this then...I don’t know. I would [have] maybe been a little hesitant, but I still would have donated. [Interviewer: Yeah, it’s a hard hypothetical question to ask.] I mean, you weigh the risk of this person having to go on dialysis and for the rest of their life, and not knowing, or you can do *this*, and you *might* get this later on, and you might not. So, I would rather help, you know. I was in a dialysis center, so I’ve seen it...”

(5025)

“... [E]ven though it increases my risk of complications, the impact that I could have immediately by changing the health of my recipient is a greater need, and would supersede that additional likelihood of complications by having both markers. I would still move forward with it.”

(5011)

Subtheme: Con: donating with two APOL1 gene variants

“I probably would have thought about it differently because knowing what kidney disease is about and what the process is, I probably would have been a *little* bit more cautious about rushing into it, if it was going to be a huge difference in my life style ... involved what it would end up causing me to do, or how it would end up affecting me. So, yeah, probably would have been a little bit more hesitant about just rushing into it.”

(5014)

“I can’t say with certainty. I think the first step that I would have done would be to talk to all of the physicians that I worked with at [the transplant center] to get *their* professional advice before I made that decision. [Interviewer: Okay. And what is making this a hard decision for you?] Again, I wouldn’t want to donate my organ if I knew for a fact or if there was, a significant amount of uncertainty on whether or not it would be effective in the recipient. [Interviewer: And what would have helped you decide?] ... Probably just *my* doctor’s overall recommendations and experience with other patients that they’ve worked with that may have been in similar situations. So just kind of getting their knowledge about prior donations that they’ve been a part of where the person donating the organ may have also had two variants, and just asking them how *their* recipient did afterwards.”

(5005)

Theme: APOL1 Testing Post-Donation

Subtheme: Pro

"I would see what I can do to prevent getting kidney disease, if I did the test and found out I actually had the gene. I'd try to do whatever I need to do to prevent any type of health issue."

(5025)

"Yes, if it would tell me, if it might shed light on my susceptibility to kidney failure."

(5005)

Subtheme: Con

"Nah. [Interviewer: Okay. And what is your reasoning for that. For not wanting to.] What's done, is done. And I wouldn't want to go in there, you all tell me I have a two. And then you're going to stress me out at 65. Hell no! [Laughing] Sorry! No, I'd much rather not know."

(5002)

Theme: Allowing donors with two *APOL1* gene variants to donate**Subtheme: Pro**

"Because I think they still should be allowed to be donors. Even though they had the two gene variants or the one. I don't think they should not be allowed. I think that would be kind of biased."

(5008)

"As long as they are well informed, and they know the potential risks that are associated with it, yeah, it should be their choice."

(5009)

Subtheme: Con

"I would probably say 'no' on that one. I know people would still want to, I know *I* would still want to. But I just think looking at the risks behind it, for both the recipient and the donor, ... those risks outweigh the rewards."

(5004)

"... I'm going to say they [doctors] should make that call. I trust they studied that, they went to school, they're doctors, and they studied their field, so they ought to know if they're putting us at risk to donate or not. So, I'm going to say, yes, let them make that decision."

(5019)

Theme: Inform Recipients

"Because it's going to impact them. ... [I]f there's a possibility that this kidney may fail because of, you know, A1 or A2 or whatever, I think they should know. You know, they may decide that they don't want to go through the transplant"

(5012)

“Yes. ... Because they need to know what’s going to affect them in the long run, or the chances of being affected.”

(5024)

Theme: Communicating *APOLI* Test Results

“It should be done when they do the first blood test, when you’re coming in when you do the bloodwork. That should be one of the tests done at that time. So at the beginning of the process. [Interviewer: Okay, so early on. Why do you think early on?] Because then that person can make an informed decision as far as if they want to continue with the process. Because why go through all of that and do it in the middle of it, ... and you find out, ‘Oh, wow!’ then you’ll be disappointed, and the recipient would be disappointed.”

(5025)

Theme: Impact of *APOLI* Testing on African American Identity

Subtheme: Positive impact on African American donors

“I think that it’s going to be a positive impact because it’s education, just like how we are trying to educate people on the reasons why to donate and try to educate them on breast cancer in African Americans, hypertension in African Americans, diabetes, I mean, it would be on the list as education.”

(5013)

Subtheme: Positive impact on community

“I think it will have a positive impact on the African American community because most people probably don’t know about the testing.”

(5008)

“I think they would accept it and welcome it because it’s another tool, like I said, to manage, to give you more information about your health and heritage, or, give you more information about your health and your genetic makeup.”

(5020)

Subtheme: Negative impact on the community

“I can think you’d probably have some pushback just because some people would feel that it’s an unnecessary test. Some people would think about the costs behind it, versus just not knowing. Again, to me it would be a good thing, but I can see people having some sort of backlash. Like pushback against it. Just because of financial factors, and then, just the idea of mistrust with the healthcare community.”

(5004)

Subtheme: “Our list”

“Negative. It’s going to have a negative impact. I mean we already have a stigma of carrying diabetes, high blood pressure, and now this. ... Our ethnicity carries a higher percentage of AIDS, and various cancers, so it’s very negative. I mean it’s like this, ‘Oh, Black people are tainted! [Chuckles] So, let’s further marginalize African Americans.’ I think it’ll do more harm.”

(5015)

“I don’t...to be honest with you, that would just, as they say, be another thing added to our list that you always hear about. I’m just going to speak about Black people. They have hypertension, they’re known to be diabetics, they’re known to be this, and that was still another thing added to the list. And so getting tested for that, I guess it would just be another thing. It’s hard to say it. It’s just something else added to our list.”

(5019)

“We have, you have to understand, all nationalities share things that they’ve been through in life. But Blacks have been downgraded so low, and targeted, we are automatically going to be on the defense like that. Automatically, a Black person picks up this paper and they are going to be like, “Here we go! It’s always something! Blacks this, Blacks this! We brought AIDS over! We brought this over! We did this!” This is how people labeled us. So what you going to do? We are going to look at this paper, like, I’m not answering, I’m not going to respond to this. This is an insult. But if it’s explained directly like, put some wording in there like, yeah, I’m not targeting you, but Blacks have the highest in the percentage, and then diagnosed with the gene 1, gene 2. If they want their wording, but everybody knows it’s new, getting the gene is that’s way over. Don’t just express Blacks. It would be better to absorb and fair to us. We won’t be like, ‘Oh! Okay, but everybody get it now, but okay, they are telling us, they are alerting us that we have a risk. So is it our food?’ It’ll question us, like, maybe we eat more or something, and then automatically being disrespectful. Like, wait a minute, getting on defense and being offended as well.”

(5024)

[^] *APOL1 = Apolipoprotein L1*

Living Donors' Questions about *APOL1*^A

APOL1-Specific Issues

- When did they discover this? This particular gene? How long ago have they had this information? (5002)
- Why are they just now getting around to studying it [the impact of *APOL1* gene variants on African American living donors]? (5002)
- Can you specifically tell me what this thing [*APOL1* gene] is? (5002)
- When did *APOL1* come about? (5023)
- Is this is a test only given to patients with African American backgrounds? (5005)
- Will they make it harder for people to donate [because of the *APOL1* gene variants]? (5015)
- What supports are in place to assure that the donors are respected and fully knowledgeable? (5015)
- What are the outcomes of your offspring [from having *APOL1* gene variants]? (5015)
- Will I be able to have kids again? (5023)
- How long will the received kidney last if tested one gene or two genes? (5024)

Preventative Care

- So, if I'm healthy, then what can I do to continue a good healthy kidney? (5000)
- But if it's in between, or at a higher risk, what can I do to prevent it [kidney disease]? (5000)
- What do I have to do to reduce my risk of this [kidney disease] happening? (5009)
- Are there changes I can make to my diet? (5011)
- What foods [should I] not eat, what [should I] eat. (5016)
- Is there anything that's within my control to try and lessen my odds of developing kidney failure? (5011)
- How would I have to stay healthy to try to avoid kidney failure? (5016)
- How would this affect me, how does this affect the recipient? (5016)
- Just the daily questions on how should I walk through life? (5016)

Genetic Test

- What type of testing am I going to go through? (5003)
- How many times a year do you have to go for it [*APOL1* genetic testing]? (5000)
- How long does it [the genetic testing] take? (5003)
- How invasive is it? (5008)
- How much blood needs to be drawn to do the test? (5008)
- [W]hat are the side effects of it [*APOL1* genetic testing], if there are any? (5003)
- How long would it take to get the results back? (5008)

Questions potential donors should ask

- How did I get this [*APOL1* gene variants]? Where did this come from? (5000)
- Okay, if I have the one or the two, how does that impact me as the donor and the recipient? (5002)
 - What is the *APOL1*? (5002)
 - How do you determine this [*APOL1* gene variants]? (5002)
- What are the drawbacks of me giving the kidney? (5003)
- [A]m I still going to be able to do the same things before I gave the kidney? (5003)
- What's the likelihood of me going through renal failure in the future? (5004)
- I would want to know all of the benefits of the testing, and the risks associated with the testing. (5005)
- I would want to know that my results would be confidential, or only released to those that *need* to know the information such as the transplant team. (5005)
- If the test were to come positive, and I have both genes, what is the likelihood, or what is the percentage, that I might actually get kidney failure, if there is even any percentage, you know? (5023)
- Will the results change overtime? Will they remain the same even if you get tested more than once? (5024)
- What are my risks of donating? (5025)
- Is there anything that I might be more susceptible to later on in life, after donating? (5025)
- Have they found anything to research that I need to be aware of, that might harm me or cause issues with my health later on in life? (5025)

AA Identity

- Why is our percentage more prone to be higher? Is there something that we're not doing? Or something that we are doing? Why? And is there anything to support information to tell us why that is? (5006)
- [W]hat is it [*APOL1* genetic testing] going to do for the African American community? (5014)
- How did this [*APOL1* gene variants] come about? If we're all born with it, if we all share the same number of chromosomes, and some of the same genes in the same planet, like how? (5015)
- What is it that I guess that's in African American or Black where it's higher in Blacks than it is in whites. Like, what is the reason? (5023)
- I mean, does their ethnic background, as far as the mixtures, make a difference in if one is more susceptible than the other? (5025)
- How long has it been since they discovered that there might be an issue with African American donors? (5025)
- How does that rate compare to non-African Americans? (5006)
- "What about white people?" Is this something that every race gets? Or is it specific to African Americans? (5002)

Insurance

- How would the insurance companies see it? (5000)
- Is the insurance going to cover the testing? (5010)
- How much of the preventative care would they pay for, or consider to pay for? (5000)
- How soon can the insurance companies add this to the roster of health care? (5000)
- Because now like Medicaid, I guess, pays for the surgery and I guess they paid for any follow up or whatever but then if something were to happen, would they want to decline you? (5012)
- How much out-of-pocket would it be for the person? (5020)

[^] *APOL1* = *Apolipoprotein L1*

Figure 1.
Participation Rate

Table 1.

Participants' Demographic Characteristics

Variable	Value
Age, y	47 +/- 14 (26–70)
Age category	
< 50 y	13 (57)
>=50 y	10 (43)
Female sex	20 (87)
Non-Hispanic Ethnicity,	23 (100)
Marital Status	
Not married	9 (39)
Separated/divorced/widowed	8 (34)
Married/domestic partner	6 (26)
Education	
High School Graduate	1 (4)
Some College	8 (35)
College Graduate	9 (39)
Post Graduate Degree	5 (22)
Adequate Health Literacy	23 (100)
Employment Status	
Employed full-time	16 (70)
Employed part-time	3 (13)
Not employed	3 (13)
Retired	1 (4)
Income	
< \$15,000	4 (17)
\$15,000 - \$34,999	2 (9)
\$35,000 - \$54,999	8 (35)
\$55,000 - \$74,999	5 (22)
\$75,000 +	4 (17)
Primary Health Insurance	
Private *	18 (78)
Medicare/Medicaid	4 (17)
No insurance	1 (4)
Health Status	
Excellent	6 (26)
Very Good	9 (39)
Good	8 (35)
Fair	0

Variable	Value
Poor	0
time Since Donation, y	8.3 +/- 3.6 (0.8 – 14)
Living Donors' Relation to Recipients	
Sibling	10 (44)
Parent	5 (22)
Child	4 (17)
Spouse	2 (9)
Uncle	1 (4)
Friend	1 (4)

* This includes 1 person with private insurance and government insurance.

^ SD = Standard Deviation.

Values for categorical variables are given as count (percentage); for continuous variables, as mean +/- SD (range). N=23.

Table 2.

Participants' Survey Scores

Variable	Highest Achievable Score (potential score range)	Mean +/- SD (range)*
Black Racial Identity: Centrality subscale	4 (1–4)	2.6 [0.4] (1.3 – 4.0)
Africentrism-Cultural Identity	4 (1–4)	3.1 [0.3] (2.2 – 4.0)
Temporal Orientation		
Present-time orientation	5 (1–5)	1.8 [0.4] (1.0 – 3.0)
Future-time orientation	5 (1–5)	2.9 [0.4] (1.8 – 4.0)
Knowledge of Genetics	9 (0–9)	6.7 [1.4] (3.0 – 9.0)
Genetics Self-Efficacy	5 (5–35)	10.4 [6.0] (5–24)
Genetics Literacy		
Familiarity	7 (1–7)	6.3 [0.8] (4.7 – 7.0)
Fill in the blank	8 (0–8)	6.9 [1.3] (4.0 – 8.0)

*
SD = Standard Deviation

Table 3.*ApolipoproteinL1 (APOLI) Genetic Testing Pros and Cons*

		Responses				Mean +/- SD ^
		Strongly Disagree	Disagree	Agree	Strongly Agree	
3.	My genetic test results could help me make better decisions about how to take care of my health. *	1 (4)	1 (4)	8 (35)	12 (52)	3.41 [0.8]
5.	Knowing that I carry 2 <i>APOLI</i> gene variants would motivate me to better watch my health. *	1 (4)	1 (4)	8 (35)	12 (52)	3.41 [0.8]
4.	Genetic testing would help me learn if I were at greater risk for getting kidney disease after donating. *	1 (4)	0	10 (44)	11 (48)	3.41 [0.7]
6.	Knowing that I carry 2 <i>APOLI</i> gene variants would help me decide whether to go for more frequent kidney checks. *	1 (4)	0	12 (52)	9 (39)	3.32 [0.7]
2.	My genetic test results could give me useful information about the risk of getting kidney disease after donating. *	2 (9)	0	9 (39)	11 (48)	3.32 [0.9]
7.	My concerns about getting kidney disease after donating would be reduced if I knew I did not carry <i>APOLI</i> gene variants. **	1 (4)	1 (4)	11 (48)	8 (35)	3.24 [0.8]
9.	Knowing whether I have 2 <i>APOLI</i> gene variants would help me decide whether to donate. **	2 (9)	2 (9)	9 (39)	8 (35)	3.10 [0.9]
11.	If I donated, after learning that I have 2 <i>APOLI</i> gene variants I would worry about the recipient's kidney transplant survival. *	0	3 (13)	16 (70)	3 (13)	3.00 [0.5]
8.	Knowing whether I had 2 <i>APOLI</i> gene variants would increase my sense of personal control over my health. *	2 (9)	4 (17)	9 (39)	7 (30)	2.95 [1.0]
13.	If I did not donate because I had 2 <i>APOLI</i> gene variants, I would feel guilty about my recipient not getting a living donor kidney transplant. *	2 (9)	4 (17)	11 (48)	5 (22)	2.86 [0.9]
1.	If I were found to carry the 2 <i>APOLI</i> gene variants, it would help my intended transplant recipient decide whether to accept a kidney from me. **	1 (4)	5 (22)	12 (52)	3 (13)	2.81 [0.8]
12.	If I learned, after donating, that I had 2 <i>APOLI</i> gene variants, I would feel guilty if my recipient's kidney rejected. *	1 (4)	7 (30)	10 (44)	4 (17)	2.77 [0.8]
10.	If I learned that I had 2 <i>APOLI</i> gene variants, I would consider not donating. *	1 (4)	10 (44)	9 (39)	2 (9)	2.55 [0.7]
14.	If I underwent genetic testing and learned that I had 2 <i>APOLI</i> gene variants, this information would be emotionally burdensome. *	1 (4)	10 (44)	9 (39)	2 (9)	2.55 [0.7]
16.	Being tested for <i>APOLI</i> gene variants could jeopardize my insurance coverage. *	3 (13)	11 (48)	4 (17)	4 (17)	2.41 [1.0]
15.	If I were found to carry <i>APOLI</i> gene variants, I would worry that the results would not stay confidential. *	4 (17)	16 (70)	0	2 (9)	2.00 [0.8]

* One participant skipped this question. Percentages are based on n=22.

** Two participants skipped this question. Percentages are based on n=21.

[^]
SD = Standard Deviation.

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